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Listening to the voices of children with autism about their primary school experience

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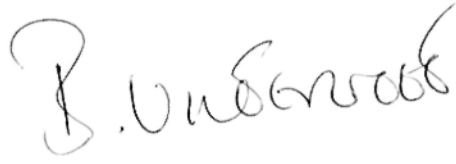
Student's Statement

I hereby declare that this submitted study is not a copy, nor duplicate of other people's works, papers or examinations. Use of sources, references, and quotes have been included in the correct format using the APA style of referencing. All relevant literature cited within the main body of work is listed in the bibliography.



Abstract

Listening to the voices of children about their school experience can give valuable insight on how a school can improve their practices of inclusion and plan effective programmes of learning and support. Gauging the views of children with autism is underexplored in research, especially in the primary age range. There is an increase in prevalence of children diagnosed with autism each year. It is acknowledged that children and young people with autism are one of the most vulnerable groups to be excluded at school. Trying to address the gap identified, the aim of the study was to gain the views from primary school aged children with autism about their perspectives of school. A qualitative research design was chosen as the best approach. Gathering the meanings children with autism made for themselves about the context of school was best informed by using semi – structured interviews as a methodological tool. To facilitate the interview process children could choose to take photographs or draw pictures of the way they perceived school. A small purposeful sample was drawn of four children, all with a diagnosis of autism, between the ages of seven and eleven years of age attending a range of settings in primary provision. Data was analysed using a thematic, interpretative approach. From the results a unique picture of each child was encapsulated from what the children said about school. Topics of interest raised by the children were diverse. Children were able to talk about their likes and dislikes, what helped and what they found difficult within the school context. Drawing and photograph elicitation methods showed success in stimulating the children's views and conversations. Methods were evaluated as to how successful they had been in eliciting the views of children with autism. Implications and recommendations for future research have been addressed.

Key words: autism, pupil voice, school experience, primary age.

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Chapter 1 Introduction

The topic of this research was influenced by my own personal experience as a teacher and the difficulties faced by schools when planning for children with an autism spectrum disorder. Autism is a hidden disability and not easy to recognise and understand (Batten, 2005). Understanding the learning style of children with autism presents a challenge for teachers. The confusing and frightening world that faces a child with autism, when they come to school, was particularly highlighted to me as I read revealing accounts given by adults with autism about their school experiences. The personal experiences, of parents with children with autism, about the challenges they faced in understanding their child's responses to the world we live in and what happened when they went to school were also enlightening. These accounts highlighted for me the importance of the need to listen to the views of the children themselves if teachers are to try and understand their experiences in trying to make sense of the world around them. By listening to the voices of children, this, in my view, would raise awareness of who they are, what they need and how they can contribute, giving essential information in order for educators to work in partnership with children to personalise programmes of learning. This chapter introduces you to the reasons behind the research project I have chosen to carry out and expands on the influences I have outlined above.

As a senior leader for seventeen years in Nursery and Infant schools in England, I observed the practice of teaching and learning in order to monitor and evaluate the quality of teaching. My observations also involved evaluating the progress children made in their learning. It became evident that teachers struggle to plan programmes of learning and support for children with autism. Teachers had difficulty in including children with autism both socially and academically within the class. Even the most experienced teachers felt deskilled and reported a variety of behaviours which they found difficult to cope with: outbursts or tantrums, strange noises, children talking to themselves, ad hoc screams, children taking themselves out of the classroom, difficulty for children in engaging in group activities, difficulty in attention and keeping on task, refusal to do anything unless linked to a particular interest, physical aggression to peers and staff, distress when someone looked at them or they thought

someone was looking at them, fascination for certain things, people, objects or places. In these situations teachers became frustrated by their lack of knowledge regarding the nature of autism and how these children learn best. The children's behaviour could be interpreted as distress, which may have resulted from the lack of understanding by teachers about the nature of autism. It could be the approaches the teachers used, were not addressing the children's possible sensory overload they may have experienced by being in a large busy school environment. In a study of teachers' perceptions of autism spectrum disorders it was found that teachers showed a lack of understanding of the social and emotional behaviours of those children diagnosed with autism (Helps, Newsom-Davis & Callais 1999). Teachers also over estimated the cognitive abilities of those with autism leading to the use of confusing teaching strategies with the potential to lead to frustration on both sides (Helps et al, 1999).

Teachers not only need to understand the nature of autism but also which strategies may be more appropriate to support the broad range of variance across the spectrum. Therefore understanding what may or may not work for any individual child is complex. The challenge then is to not only to understand the nature of autism, but to be professionally informed as to how these autistic characteristics manifest themselves in any one individual child in order to meet their particular needs and learning style. It could be said that this is the challenge in teaching any individual. However, this is exacerbated when considering those children with a range of different autistic characteristics. I will explore in more detail the nature of autism and links to teaching strategies in Chapter 2.

Reading personal accounts of autistic adults about their lived experiences, in comparison to books written by professionals, has given me a more in depth insight into what it could be like for an autistic individual at school. This view is supported by others. Clare Sainsbury (2009) reports that many teachers have told her that autobiographical accounts have enabled them to empathise to a much greater degree about their autistic students and although practical advice can be gained from books written by professionals, it is these individual accounts that lead to greater understanding about what it is actually like to be an autistic child at school. For example, an account written by an autistic thirteen year old describing the reasons behind his behaviours highlighted how different strategies offered to support him

affected him. He reported that some strategies, for example visual timetables, were actually a source of distress (Higashida 2007). The boy acknowledged that for some individuals such strategies may actually help but for him they were restrictive and when people showed him pictures about a forthcoming event, with the view that this would help him with the structure of what was happening next, it actually spoilt his fun (Higashida, 2007). Other personal accounts written by autistic adults, looking back at their lives give a picture of how confusing it was for them during their school years and raise the readers awareness of the negative effects of being bullied, marginalised and made to feel different (Sinclair, 1992; Grandin, 1995; Sainsbury 2009).

Parental accounts have also highlighted the confusing world of school that their children experienced (Mont 2002, Osei 2010). They described how distressed their children became and the difficulties educators faced in finding the right way to include their children in mainstream schooling (Mont 2002, Osei 2010). Both accounts detail how teachers were ill equipped to meet the needs of their children and had difficulty planning an effective programme that took advantage of the special interests the children had (Mont 2002, Osei 2010).

Acknowledging that personal accounts make a difference to our levels of understanding, encouraging pupil voice and listening to children could be said to be a key way of being able to understand their individual needs and personal ways of learning. Finding meaningful ways of communicating with children so that their views are listened to and respected is imperative (MacConville, 2007). All children have a right to be included and as professionals teachers need to give sufficient time for children to express views in their own ways. 'Pupil Voice' as a concept has emerged as a way to address the rights of children to express their perspectives and has come to the fore as the imperatives of the United Nations Convention of the Rights of the Child (UNCRC, 1989) and the United Nations Convention on the Rights of People with Disabilities (UNCRPD, 2006) impact on policy and practice. The aim is to address children's and adults rights to be involved and to be full participants in matters that directly involve them.

Listening to the views of children about their school experiences can give valuable insight on the ways a school can improve their practices of inclusion and plan effective programmes of learning and support for children (Carrington & Graham 2001, Messiou 2002, Humphrey & Lewis 2008, Saggers, Hwang & Mercer 2011).

It is suggested that studies gaining the pupil perspective of children on the autism spectrum are underexplored (Humphrey & Lewis, 2008; Jones, English, Guldberg, Jordan, Richardson & Waltz, 2008). Research can raise important questions as to how schools can improve inclusion both socially and academically for autistic pupils and this is a crucially important issue as numbers of pupils with autism spectrum disorders rise in mainstream settings and concerns regarding their experience of school increase (Humprhey & Symes 2010). The criticism of current research has been that " there has been very little research on soliciting the views of children and young people on the autism spectrum specifically" (Jones et al, 2008, p43). Having searched a range of online journal databases using key words – 'autism, ASD, pupil voice, voice, pupil perspectives, primary age range, Infant children'- revealed only a small amount of studies published to date and all were focused regarding the perspectives of secondary aged children. Lack of research in the area of primary schooling is surprising. Especially when it is so strongly recognised today that learning in the early years of development can have such a profound effect on later achievements. There is a suggestion that a lack of research into the views of children with autism spectrum disorders may be due to the condition itself (Brewster & Coleyshaw, 2010). I will expand on what current research has found out regarding the perspectives of children with autism (albeit secondary aged children) in chapter 2.

A recent review as to what kind of research is being conducted, concluded that the majority of research in the field of autism is concerned with diagnostic assessment of children, underlying causes, biological factors and questions around cognition function (Pellicano, Dinsmore & Charman (2014). These authors asked the views of different practitioners and autistic adults on what they thought were important areas to research and the general consensus was that research should focus on 'those areas that make a difference to people's day to day lives" (p1). The majority of those questioned favoured research, which gave insights into what would benefit and impact on their lives directly. Practitioners wanted more research to look at more effective strategies

to support learning. Coming as I am, from a practitioners point of view my interest is directly related to the experience of primary aged school children in the classroom. I am passionate to gain more knowledge about how inclusive practice can be improved and how a greater understanding of what learning is like for children with autism could render mine and others practice more enabling and effective for those children.

To this end I hope to address, in a small way, the gap that exists in research findings surrounding the perspectives of primary aged children with autism on their school experiences. This in turn may broaden practitioners understanding of autism itself and of the ways they can plan more appropriately to support all children.

I also acknowledge the difficulty of accessing the views of young children with disabilities and the ethical considerations involved are well documented (Cuskelly, 2005; Lewis, 2002). These particular challenges will be discussed in greater detail in Chapter 3 when considering what methodological approach should be taken in this particular study.

With the increase in prevalence of children on the autism spectrum and the awareness that this is one of the most vulnerable groups to be excluded from school (Batten 2005, Humphrey & Lewis 2008) highlights how important it is to address what the children with autism have to say about their experience of school.

For me the following words from Stephen Dedridge (2007) sum up my reasons for this project:

> It is important to listen to children with ASD and find out how they feel and think and what they understand. This may prove a challenge because of their social communication needs. Nevertheless, it is worth making an effort because without establishing some insight into how these children understand and perceive their world our attempts to address their needs are unlikely to be successful. (p37)

This study aims to gain the perspectives of primary aged children with autism about their school experiences and the research questions to be explored are:

What do primary age children on the autistic spectrum say about their school experience?

What experiences help and support them?

What experiences do they find challenging?

Chapter 2 - Literature review

2.1 Introduction

This chapter aims to review knowledge and relevant literature in the three key areas of Autism, Education and Pupil Voice. A historical and current view of the nature of autism is described in the first section. Different educational strategies linked to the teaching and learning of children with autism will be discussed in the next section. Pupil voice in the context of education and autism will be reviewed in the last section.

2.2 The Nature of Autism

Historical Background

Leo Kanner (1943) a child psychiatrist, working in America at the John Hopkins University Hospital was the first person to introduce the term Autism. In a study of 11 children (8 boys and 3 girls) Kanner, recorded in detail, his own and parents observations of the children. He identified common characteristics which he then termed "inborn autistic disturbances of affective contact" (Kanner, 1943, p.250) describing these as a syndrome that differed from schizophrenia substantially, which some of the children had been diagnosed with previously. Some children had also been labeled feebleminded or idiots, however he concluded that the children possessed cognitive potential, astounding vocabulary and excellent memories. Characteristics identified were the desire for aloneness and sameness, the anxious or impervious relationship with others and obsessive repetitiousness.

At virtually the same time as Kanner's study, an Austrian child psychologist, Hans Asperger (1944) observed that some children had similar characteristics, to those identified by Kanner, of personality, ability and behaviour. Social maturity and social reasoning showed delay in some areas of verbal and non-verbal communication in contrast to having intellectual abilities within the normal range. Children lacked empathy and understanding of others' points of view, there were some unusual patterns of speech and even though they sought friendship they had difficulty making

friends and keeping them, so were socially isolated. This then became known as Asperger's syndrome.

Current perspective

The idea of a continuum emerged later, as many did not fit the criteria of classic Autism or Asperger Syndrome and children were said to have an Autism Spectrum Disorder (ASD) if they displayed criteria within a triad of impairments (Wing & Gould, 1979). Within the continuum of ASD sub groups, who share differences to a greater or lesser extent in the triad of impairments, were also identified – Aspergers, high functioning autism, semantic pragmatic disorder (SPD), atypical autism and pervasive developmental disorder – not otherwise specified (PDD-NOS). The triad of impairments describe characteristics as follows: Differences in the ability to understand and use non-verbal and verbal communication where individuals may not understand the purpose of communication and make very little or no communication with others or show any interest in others at all. Individuals may have delayed speech development and limited use of gesture and eye contact resulting in the possibility of problems with the social conventions of conversations; Differences in the ability to understand social behaviour and interactions with others whereby individuals may actively avoid others and may show more interest in objects than people, find turn taking difficult and may fail to read and understand others feelings and needs. These individuals, therefore have fundamental difficulties understanding social behaviour, reading social signals and responding appropriately to social encounters; Differences in the ability to think and behave flexibly whereby play may be isolated, playing alongside rather than with others. Individuals may develop special interests and may have extreme reactions to change (Jones, 2002). In addition to these characteristics there may be an over or under sensitivity that may affect any one or more areas of sensory perception (Jones, 2002) e.g. sensitivity to different foods, noise and touch (Kanner, 1943).

Diagnosis

The diagnostic tool most commonly used is the Diagnostic Statistical Manual (DSM) of the American Psychiatric Association (APA) which has recently changed criteria

from a categorisation system within the umbrella of Pervasive Developmental Disorders - DSM IV (APA, 2000) to one using a spectrum of severity under the umbrella of Neurodevelopmental Disorders - DSM V (APA, 2013). Contentiously this has removed the separate category of Asperger's, aligning characteristics with the diagnosis of high functioning autism. The criticism of this diagnostic tool is that it is based on a deficit medical model and although the latest version links severity levels to levels of support it does not take into account any links between environmental factors and levels of functioning (Norwich, 2013). The International Classification of Functioning (ICF) developed by the World Health Organisation (WHO) is based on a broader understanding of the complex relationship between biological, social and psychological factors designed to base identification on the interrelation between health conditions (disorders/diseases) and contextual factors (environmental/personal) focusing on functionality of what a person can do in any one particular environment (Norwich, 2013). Norwich (2013) goes onto suggest this has huge potential in the field of education but that in its current form is not specific enough to educational settings. Another consideration in this diagnostic debate is how much the change in diagnostic criteria may influence the prevalence rates of Autism. See later in this chapter for the discussion regarding prevalence rates.

Additional comorbid factors

In addition there may be comorbid factors associated with a diagnosis of autism such as additional difficulties identified in behaviour e.g. Attention Deficit Hyperactivity Disorder (ADHD) and also level of cognitive function. There is debate over identified intellectual ability with Rutter (1978, cited in Jones, 2002) suggesting that 75% of children with a diagnosis of autism also have learning difficulties. However, others suggest there are a greater number of children with autism, than previously thought, identified as more able (Baird, 2000 cited in Jones, 2002) and more recent thinking is that there is a broad range of ability from low to high (Jones, 2002).

Autism has been described as a "highly heterogeneous disability with regard to level of functioning" (Harrower & Dunlap, 2001, p.765). Therefore, it is imperative for educators to understand this diversity in each child, that autistic characteristics

manifest themselves in different ways. With this understanding different requirements for teaching and learning are fundamentally important.

2.3 Statistics and outcomes in relation to children

Autism is a developmental disability affecting the ways a person communicates and relates to the people around them and is a lifelong condition (Batten, 2005). Statistics regarding prevalence vary between sources and it is difficult to determine an exact figure due to difficulties in accessing accurate information. However, research reveals there are as many as 1 in 100 children with an ASD and there are over 700,000 people in the UK with autism (Baird, Simonoff, Pickles, Chandler, Lucas, Meldrum, Charman, 2006).

In England, 28% of children who have a Statement of Educational Needs have an Autism Spectrum Disorder. Autism is the most common primary need identified amongst pupils who have statements of special educational needs, over 8% higher than any other special needs category. When numbers of school action plus cases are added to those with statements, numbers of children identified with autism increase by an average of 7.5% a year, this percentage being higher than any other special educational needs (SEN) category (DFE, 2014a). No conclusive reasons have been given for this increase, although better assessment and broader diagnostic criteria have been muted (Baird et al, 2006).

There is a suggestion that more able children with autism work out strategies to cope at school and therefore go unidentified, so prevalence figures could be even higher (NAS, 2006 cited in Humphrey, 2008). A sad reality is that children with autism are 20% more likely than their peers without any SEN to be excluded from school (DfES, 2006 cited in Humphrey, 2008) and have a higher rate of mental health problems than other groups of children (Kim et al, 2000 cited in Jones et al, 2008)

There is no government data, regarding those children with ASD's achievement in schools, as national SEN data does not include attainment for different SEN categories. The likelihood that children with autism are not reaching national averages

in attainment for english and maths, could be inferred from the high percentage of children with autism receiving support through statements and school action plus, as attainment is the main basis on which allocating statements is judged. Research asserts that;

> ...school is one of the most challenging environments for children on the autism spectrum because of the social demands and potential for sensory overload (Jones, English, Guldberg, Jordan, Richardson & Waltz, 2008, p17)

2.4 Teaching and Learning - educational strategies

There are many challenges that all children meet within the classroom situation. From my experience as a teacher these might include listening to and following instructions, complying to routines or changes in routine, the level of noise, the organisation of the day (timetabling etc), the movement around the room, the seating arrangements, how questions are phrased, the general use of language and collaborative and co-operative groupings. For a child with autism the challenges are considerably more demanding as they struggle with social interaction and communication.

Social learning theory suggests the child attends to others behaviour and uses it as a model to then adjust their own behaviour (Vousden, Wood & Holliman, 2014). However, this would be more difficult for a child with autism as they do not pick up intuitively or understand the reasons for others behaviours (Kirk, Gallagher, Coleman & Anastasiow, 2009). An alternative learning theory suggests that social interaction underpins the process of learning and that learning is social in nature (Vygotsky,1978). This social constructivist theory of learning suggests that social activity is crucial so that we reflect on what is being learnt and internalise that knowledge to make it our own. The gains of co-operative learning are well documented e.g. talking through a maths problem to gain deeper understanding, working together to problem solve, working together to create a play, song or dance sequence. However the level of social interaction in these tasks may bring a barrier to learning for those with autism. Children on the spectrum can struggle to take on others points of views and they may see things in a literal sense rather than an

imaginative one and may use pedantic language which is off putting to others to work with (Atwood, 2009). Children also may have difficulties initiating, sustaining and responding to social interactions and for some communication is severely impaired (Fortuna & Davis, 2014). When learning occurs for those with autism it is not mediated by social understanding and therefore children with autism present challenges to teachers that differ from what teachers would normally expect (Tutt, Powell & Thornton, 2006):

> The issue here is that autism creates a context for developing learning and teaching that cannot rely on the template of the usual assumptions and predictions and subsequent teacher actions and reactions (Tutt et al, 2006 p,70)

Any educational approach therefore has to take into account the idiosyncratic needs of the individual child (Harrower & Dunlap, 2001) and it must include the development of ways to make communication with those with autism more effective whereby "Generalist teaching principles often have to be discarded in favour of individually tailored strategies and tactics" (Tutt et al, 2006 p, 70)

Many different educational strategies and approaches have been developed to support children with autism in both their social and academic development; TEACHH, visual timetables, social stories, behaviour plans, use of picture exchange communication systems (PECs) to name a few (Dedridge, 2007; Fortuna & Davis, 2014; Jones, 2002; Kirk, Gallagher, Coleman & Anastasiow,2009). No one method encompasses all the characteristics that a child with autism might exhibit (Jones, 2002). Each strategy may try to address a different characteristic, but it is more often the case that schools may adopt an eclectic approach using one or more or parts of any one strategy (Atwood, 2009; Harrower & Dunlap, 2001; Jones, 2002; Westwood, 2011). It is difficult to know which one to use and even more difficult to know which may be the most effective.

Is there a link between which strategy to use and the underpinning psychological theory behind autistic characteristics? Rona Tutt, Stuart Powell and Mary Thornton (2006) reviewed a number of well known educational approaches. Four discrete approaches – Higashi; Lovaas; Option and TEACCH and also two eclectic

approaches - SPELL and a Local Educational Authority (LEA) specific one. In an attempt to describe links between psychological theories of autism and whether these underpinned educational practice, this study sought to increase understanding of any efficacy of approach. Their review used four psychological theories upon which to base their judgements: difficulties with 'interpersonal relatedness' as a social dysfunction affecting cognitive development (Hobson, 1993); theory of mind – a lack of empathy and seeing others points of view seen as a cognitive disorder affecting social functioning (Baron-Cohen,1995); problem of executive functioning seen as a difficulty in learning and planning when problem solving (Ozonoff, Pennington & Rogers, 1991) and difficulties in developing a sense of central coherence (Frith, 1989). From their review they were unable to draw any firm conclusions as to how effective any one of the approaches were and how they linked to psychological theory (Tutt et al, 2006). The conclusion to the review suggested that any educational approach should be based on principles of how children with autism are able to respond to teaching and learning situations and what knowledge and skills would be worthwhile for them to learn (Tutt et al, 2006).

In an extensive review of research evaluating educational interventions for children with autism, a similar conclusion to that of the previous authors was drawn, in that no conclusive evidence was found to support any one approach, also concluding there was no methodologically sound evaluation that provided such evidence and that more research was needed (Jordan, Jones & Murray, 1998). Jordan et al (1998) made the point that autism is so variable that a child may need more than one approach and that they may benefit from different approaches at different times in their development. Their conclusions were that any good educational programme should address areas of social interaction and communication and should build on a child's interests and strengths in order for skills and aptitudes to flourish and that most of the research did not have this broad educational focus (Jordan et al, 1998).

In addition care needs to be taken about the ways in which an approach is implemented in order to have a positive effect. For example, social stories, an approach used to develop social understanding can give key information in a supportive reassuring way about social situations. It is suggested that such stories should also be used to acknowledge the achievement of the child when praising a

situation. Otherwise they can have a negative effect when only used to talk through improving behavior (Dedridge, 2007). Behaviour plans may be limited in their success in their effort to improve or change behavior once rewards are lessened or cease. Therefore it is important to teach social understanding alongside social conformity in a meaningful way for the child (Dedridge, 2007).

Summary

Research shows that teachers of primary aged school children find it extremely challenging to plan for children with autism (Harrower & Dunlap, 2001) Teachers often have misconceptions about the nature of autism and lack knowledge of different behaviours and teaching strategies (Helps, Newsom, Davis & Callais, 1999). The impact of which show children are losing out because of this lack of understanding and confusion over what constitutes appropriate provision (National Autistic Society [NAS], 2003). A large number of strategies and approaches exist that may address one or more characteristic of autism (Jones, 2002). Research has so far not shown that any one of them is more effective than the other (Jones et al, 2008; Jordan et al, 1998; Tutt et al, 2006). It is also suggested that care needs to be taken when implementing any plan as some strategies, depending on how they are used, may have a detrimental effect rather than the positive one hoped for (Dedridge, 2007). It is therefore important to understand the nuances of each child in order to plan appropriate support. Teachers in trying to plan for what approach to take must have an informed understanding of the autistic characteristics, the intellectual ability and any additional difficulties each child may have (Jones 2002). They must appreciate the impact these identified characteristics may have on the child's personality and behavior and eventually, their learning (Jones, 2002).

A key point made by Jordan et al (1998) focuses on the ways in which teachers recognise the strengths and areas to develop in any one child. This is particularly pertinent when considering children on the autism spectrum. In order to be able to do this more effectively developing effective relationships is seen as especially important for those with autism, "... this relationship is crucial and needs to be achieved before any effective teaching and learning can occur" (Jones, 2002, p.2). Therefore in order for us to build this relationship we need to develop ways to listen to children in a

meaningful way. It is also not just about listening but enabling voices to be heard and acted upon.

2.5 Pupil Voice

> The term 'pupil voice' refers to ways of listening to the views of pupils and/or involving them in decision making (DFE, 2014b p2)

This particular definition is outlined in the statutory guidance for 'Listening to and involving children and young people' (Department for Education [DFE], 2014b) in England and is directly underpinned by the UNCRC's article 12 (1989) which says:

> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. (p5)

The UNCRC is an important historic international convention that recognises children's rights for the first time (Klein, 2003). Although the United Kingdom (UK) government has ratified the Convention it has not been incorporated into national law so there is no statutory duty to comply with it, only a commitment to pay 'due regard' when developing any new policies and legislation (DFE, 2014b). DFE guidance on pupil voice and SEND is statutory, i.e. governed by law (DFE, 2014c. Each guidance outline that the UNCRC and UNCRPD principles underpin the requirements of both regarding pupil voice. The language surrounding what is statutory or not is ambiguous and confusing. What message is the Government then sending to local authorities and schools who are required to develop their local policy and practice based on this DFE guidance?

2.5.1. School Improvement

A broad range of research has highlighted how when we are able to enable pupil voice in a meaningful way this has far reaching affects on improving whole school effectiveness as well as improving the teaching and learning experience in the

classroom (Flutter & Rudduck , 2004; Flutter, 2007; Martin, McGregor & McKenley, 2004; Rudduck & Flutter, 2004). In the context of schools, Rudduck & Flutter (2004) suggests that 'getting closer to learners' in order to understand their experiences and respect their perspectives leads to a sense of collaboration, sharing the responsibility for the quality of teaching and learning. Flutter (2007) also suggests that when schools engage pupil voice this improves the teaching and learning experience for both teachers and children: for children in that self esteem and independent skills are improved and for teachers that they understand better the needs of the children and therefore plan more appropriately. The Euridem Project explored the link between student participation and school improvement in 4 different European countries and suggests that

> When pupils had a voice and were accorded value, the school was a happier place; when pupils are happy and given dignity, they attend more and they work more productively….. (Davies & Kilpatrick, 2000 cited in Klein, 2003 p17).

Other benefits of listening to children and giving them a voice have concluded that it gave pupils a sense of ownership, enhanced their levels of communication and collaborative skills, their personal and social efficacy which then had a positive impact on all areas of their learning (Hannam , 2001, cited in Klein , 2003).

2.5.2 Special Needs and Disability

Are all groups of pupils given the same opportunity to voice their views? Although the UNCRC highlights the rights of all children, it is the UNCRPD (2006) that has re – emphasised listening to the views of disabled children. The UNCRPD (2006) was borne out of the need to combat stereotypes, prejudice and the marginalisation of people with disabilities and emphasises children's rights to express their views in article 7.

The UNCRPD (2006) promotes equal opportunity for those with disabilities to influence and participate fully in formulating policy and practice. It recognises the importance of autonomy and independence including freedom for any child or adult to make their own choices and be active in things that directly involve them. The

way the Convention's principles are then translated into policy and practice and the strategies developed to listen to disabled children's voices are crucial to children with disabilities in the way they can participate and be involved in decisions regarding services and support that affect them.

The recent *Children's and Families Act 2014 – Improving Outcomes*, impacts on laws that protect vulnerable children. The Act includes the culmination of an extensive review of how Special Educational Needs and Disabilities (SEND) is identified, managed and funded across local authorities and schools. The statutory duties and guidance, implemented from September 2014, requires local authorities and schools to pay 'due regard' to the new SEND Code of Practice (DFE, 2014c). In the past and more recently the government in England has been criticised for not taking into account the views of disabled people when developing policy (Armstrong 1995; Hansen 2014). This recent review boasts full consultation with all parties including the views of children and parents and in some way this may have happened as there are noticeable differences between the 2012 draft, put out for consultation, which made little or no reference to seeking the views of children and the published and ratified new statutory SEND code of practice (DFE, 2014c) that highlights a "clearer focus on the participation of children and young people and parents in decision-making at individual and strategic levels" (p13).

How will this then be translated at a practice level by local authorities and schools? Will children really be part of the consultation process that involves them with making the specific plans of support they need, or in the review process of formulating new programmes of support? Could the concern voiced by Derrick Armstrong (1995), albeit about an earlier code of practice, questioning how much consultation with children actually takes place in practice, remain relevant today? In the past there has been the suggestion that a gap does indeed exist between policy intention and real experiences (Parry, Rix, Kumrai & Walsh, 2010). They argue that if we are to stop the marginalisation of disabled children and young people then we need to recognise pupil voice to be fundamental to participation and that "Innovative responses to supporting young people… depend on listening to their views and using their ideas about how things should change" (p4).

There is an important question to consider when thinking about how much involvement a child or young person identified with SEND is given in developing their own individual education plans (IEP). Bergin & Logan (2013) suggest language used in policy formation is ambiguous and "leaves pupils with SEN vulnerable to being excluded from the process" (p80). They go on to say that it is not enough "that pupil involvement is 'good practice' but rather that it is an absolute imperative and integral part of the IEP preparation"(Bergin & Logan, 2013, p80). There are no practical guidelines as to how pupil's views should be sought and interpretation of the Act and guidelines are left to Local authorities to develop their own policies and practice. There is also no recognition of the how the differences between each category of need may impact on how we gain the views of children and the different challenges this raises i.e. moderate learning difficulties, visual impairment and autism for example. As mentioned earlier this is left to individual local authorities and schools to determine.

Questions arise as to how do schools listen to the views of children identified with a SEND and in particular, for the purpose of this study, those on the autism spectrum and also what can we learn from listening?

2.5.3 Research – Autism and Pupil Voice

Many studies have highlighted the fact that schools can improve their practice of inclusion and plan more effective programmes of learning and support for children with disabilities by developing processes to listen and so gain the pupil's perspective of themselves as individuals at school and of school practice as a whole (Carrington & Graham, 2001; Curtin & Clarke, 2005; Humphrey & Lewis, 2008a, Messiou, 2002; Saggers et al, 2011). However, disability studies researching pupil voice is still an underexplored area (Humphrey & Lewis, 2008b; Cook, Swain & French, 2010). Seven studies were found, taking place between the years 2000 and 2014. These studies researched the views of children and young people with autism about their perspectives of school. All seven studies explore views of secondary aged pupils (ranging from 11 to 18 years old) and hence an identified gap in gaining the perspectives of those children at Primary school (ranging from 5 to 11 years of age).

What did the research find out?

Struggles with identity were highlighted as pupil's tried to mask their differences (Carrington & Graham, 2001) or expressed a wish to be 'normal' (Humphrey & Lewis, 2008b; McLauglin & Rafferty, 2014). Environmental factors had the potential to increase levels of stress and concentration such as noise, busyness, seating arrangements (Carrington & Graham, 2001, Hill, 2014). Peer relationships featured strongly as either disabling with high incidences of bullying reported leading to a feeling of isolation and anxiety (Carrington & Graham, 2001; Humphrey & Lewis, 2008b; Humphrey & Symes, 2010) or enabling, where friendships were developed, these could be supportive (Humphrey & Lewis, 2008b). Characteristics of autism were found to be a significant factor in influencing relationships with peers (Humphrey and Lewis, 2008b) and in an earlier study social problems were quite prevalent, even if the autistic tendencies were seen as quite mild, with the suggestion that educators should never underestimate problems associated with mild ASD (Conner, 2000). Conclusions drawn from these studies highlighted the need for social support and understanding and that schools should do more to accommodate individual needs.

Saggers et al (2011) found that the most significant factor as to whether the students felt included was the attitudes of teachers and their ability to understand their strengths and weaknesses by active listening. They believe that listening to the voices of students would enable schools to "collaboratively create supportive learning and social environments" (Saggers et al 2011, p 173). Humphrey & Lewis (2008a) carried out a case study of four schools, which asked the question, what does inclusion mean for pupils with autism in the mainstream. They concluded that the essential factors were clear leadership and inclusive ethos, good communication between all those staff involved with each child identified with autism, clarity of responsibility as to who was planning and who was supporting each child and, finally, consideration of specific group and individual needs.

2.6 Summary

Research during the last 15 years has been conducted, including all children, on pupil voice. Findings show the way pupil voice can have a positive impact on school improvement both for the individual children and for the whole school. However, questions have been raised suggesting that disabled children's views are being marginalised (Flutter & Rudduck, 2004, Rudduck & Flutter, 2004) . During the last 10 years disability studies have turned attention to listening to pupil's voices.

However, there is disparity between the amount of research conducted between the different groups of special needs and a lack of studies in the field of autism.

The number of children diagnosed with autism is increasing, although the exact cause of this is not conclusive (Baird et al, 2006). Autism as a SEND category has the highest number of statements of special needs awarded, as compared to other categories in England (DFE, 2014a). Exclusions from school for children with autism are 20% higher than any other group. It is well documented that children with autism suffer from mental health issues and that this carries on into adulthood.

The few research studies found, relating only to secondary aged pupils, identified some environmental issues that were bothering the young people that had the potential to be quickly addressed. Longer term improvements that schools could make to support young people with autism suggested clear leadership and the development of a whole school ethos valuing inclusion would give children a sense of belonging rather than the feeling of isolation and exclusion (Humphrey & Lewis, 2008a)

Chapter Three - Research Methodology

3.1 General Approach and Design

As an early years Infant and Nursery teacher for 23 years I am looking to find answers to problems I have encountered in the classroom. I am guided by my practical experience, in order to come up with an answer to a problem (Robson 2011).

The problem was to find out what children with autism could tell me about their perspectives of school. By listening carefully to their experiences, I was looking to see how children constructed and made sense of their world (Robson, 2011). My approach, for this study, came from a social constructivist point of view. I was interested in the complexity of the children's views (Creswell, 2007). "The goal of research, then, is to rely as much as possible on the participants views of the situation" (Creswell, 2007, p.20). I recognise that my teaching background may have influenced the way I positioned myself within this research (Creswell, 2013). Also, as to the way in which I interpreted the children's perspectives and I was aware of this influence in considering any bias in the results and analysis.

This study was a qualitative research project as the design produced data that was non-numerical and the analysis focused on meanings in context where openness and receptivity are important (Robson, 2011). I used inductive methods to interpret the phenomena being studied in a natural setting (Robson, 2011), which is a characteristic of a qualitative study. Seeking the opinions of children and letting them tell me their story was also seen as a narrative of the lived experiences of school. My focus centred on the perceptions and views of the participants, gathering together multiple perspectives (Cohen, Manion and Morrison, 2007). Narrative inquiry enabled me to use a less structured set of questions and allowed the children to set the agenda resulting in "rich textual or observational data" (Elliot, 2005, p.2). An extended story about a significant aspect of a person's life, such as schooling is one way to define narrative (Chase, 2003).

I also considered whether this study could be defined as a Case study but as my research questions were not in depth 'how' or 'why' questions (Yin 2009) I decided it did not fit my criteria . I saw this as an unfolding, emerging type of study and not one

that generated any theory (Punch, 2000) but rather produced a description of the child's experiences and the ways they expressed themselves. My research includes aspects of descriptive and explorative design. Explorative, as no previous studies have been found focusing on the research area of primary aged school children with autism and their perspectives of school. Descriptive, as this study does not try to answer questions 'why', rather questions about 'what' will the children tell me and 'what' does this tell us.

3.2 Research Methods (Data Collection)

Researching Children's Perspectives

Historically, social and psychological viewpoints have thought of children as not having the competency to reliably describe and understand their own world (Fraser, 2004). In the arena of research "children [are] often denied the right to speak for themselves either because they are held as incompetent in making judgements or because they are thought of as unreliable witnesses about their own lives" (Qvortrup et al, 1994, p2 cited in Fraser, 2004 p16). Clark & Moss (2004 cited in Fraser, 2004) assert that children are 'experts in their own lives' and are skilful communicators and meaning makers. I support this viewpoint having worked with young children for many years. I have observed how they make decisions for themselves, how they explore their environments to seek explanations and how they test their own theories in making sense of their world. However, I acknowledge that to tap into the processes children use, in order to facilitate their learning is difficult and complex. It may be that they do not have the breadth of language to express or explain their actions. To this end researching the perspectives of children becomes more difficult especially with children on the autism spectrum. The suggestion is that the methods used with adults should be adapted to be more inclusive of children and that research should be Participant friendly rather than just child friendly (Fraser, 2004). I have long advocated that children's learning is enhanced when educators make their teaching real and especially when linked to the child's own experience. I feel this should be the same when we research their views and agree with Fraser (2004) when she describes the ways research should be done 'with' children not 'on' children (p19) Research methods should play "to the strengths of the research participants" (Clark & Moss,

2011 p4). Disabled children's views are even more marginalised than their peers and barriers exist in recognising their expertise (Clark & Moss, 2011). These authors have developed a 'Mosiac approach' that involves observation and conferencing techniques amongst others. Although the authors' work was mainly with pre-school children, the suggestion was that these methods can be used with different age groups. I agree with Clark & Moss (2011), that as children have many creative ways to express themselves we need to use creative ways to hear their 'voices'. Using children's drawings or using photographs to elicit conversations have been suggested by other researchers (Fielding, 2007; Kaplan, 2008; Leitch, 2008;Porter, 2009; Thomson & Gunter , 2007; Wang & Burris, 1995). With this in mind the suggestion of a multi - method approach that can open up different modes of communication to "reveal the complexities of lived experiences" (Clark & Moss, 2011 p6) was something that has influenced the methods I have chosen to carry out this research project. The suggestion is that a formal interview may not elicit the richer narrative that I hoped for. By letting participants use photographs they have taken themselves, or drawings, was to facilitate the interview situation and make it more accessible to those with autism.

Interview

As this was a qualitative design with the main focus on the 'voices' of children, I decided interviews would be the best option in order to elicit children's perspectives. I used this as the main methodological tool to gather children's views rather than questionnaires, as I wanted to use a more multi sensory approach. An interview "is a flexible tool for data collection, enabling multi-sensory channels to be used: verbal, non-verbal, spoken and heard" (Cohen et al 2007, p.349). This infers that both the spoken word and body language can be interpreted and I thought this was particularly important when interviewing children with autism in order to capture a richer source of data. Interviews allowed for a controlled way of collecting data, but at the same time allowed flexibility and spontaneity, as the children were able to make choices about the way in which the interview was conducted. This allowed the children to makes sense of their world in a way that was meaningful to them (Cohen et al 2007). I considered using unstructured interviews as they possibly give a chance for greater depth (Fontana & Frey, 2005). However, as the interviewees were on the autism

spectrum, of which one aspect is difficulties in social communication, I chose to use semi-structured interviews, with an interview guide to act as a prompt. Semi structured interviews allowed questions to be pre thought and also allowed me the flexibility to pose supplementary questions throughout the interview, linked to responses (Basit, 2010). Care was taken when generating questions so that the language used would be accessible by the interviewees (Elliot, 2005). This is particularly pertinent for children on the autism spectrum as one of their difficulties may be interpreting what they are being asked. When selecting questions I considered the suggestion that open-ended questions may confuse children with autism (Harrington & Foster, 2013).

I tried to evaluate the type and range of questions asked, as much as I could from the information given in current research papers, that have explored the experiences of children with autism. Bearing in mind the research was with secondary aged pupils, coupled with my own experience of working with younger children, I put together some straight forward open ended questions as a guide (appendix i). Thus anticipating that I would be responsive to the participants in the use of prompts. Susan Chase (2003) places importance on developing an interview guide even if carrying out unstructured or semi – structured interviews. She suggests that the guide will ensure you have thought of all the areas you would like to be covered well in advance. The guide acts as a prompt and that listening is the essential part of the interview so questions can be asked which arise from the interviewee's story (Chase, 2003).

Researchers have used different ways of eliciting responses during interviews especially when interviewing younger children: pupil diaries have been used as a starting point for discussion (Humphrey & Lewis, 2008 a & b), while drawings and a 'message in a bottle activity' were used in a similar way in a study with primary school children (Messiou, 2002). Kyriaki Messiou (2002) found this was a reliable way of drawing out children's responses and the stories they had to tell. Brewster & Coleyshaw (2010) in a project consulting children and young people with autism about their participation in leisure activities, assert that research gaining the perspectives of children with autism is highly neglected (Beresford et al, 2004, cited in Brester & Coleyshaw, 2010). It was suggested that the difficulty of consulting children and young people, to gain their views may be due to the condition itself

(Preece, 2002, cited in Brewster & Coleshaw, 2010). Measures then taken to address this could include use of visual prompts and individualised communication (Brewster & Coleyshaw, 2010; Leitch, 2008; Lewis & Porter, 2004).

With this is mind I wanted to make sure each participant communicated their responses in a way that was best for them. In my experience visual representation is often important to children with autism and I wanted to use ways that had the potential to engage them. Photo elicitation has been suggested as a method of empowering those in marginalised groups as well as facilitating the interview process (Wang & Burris, 1994; Kaplan, 2008). Kaplan (2008), in a study with children with moderate learning difficulties and challenging behaviour, goes on to suggest that photos can be used to explore and share the perspectives of school. This is more than just 'consultation'. Rather it is a way of actively involving pupils in a process, which potentially could improve their experiences. Hill (2014), observed that secondary aged participants with autism found using photos to elicit their perspectives helped them as 'aide memoires' (p87). The participants also reported that the photos helped them to discuss aspects in more detail. By trying to involve my participants as much as possible this may play to their strengths in representing themselves. Therefore, I gave them a choice of how they would like to facilitate talking to me. Either to show me around their school taking their own photos of things that were important to them and things they might not like or to draw pictures of what school meant to them.

Success in gathering in depth responses are reliant on the ability to create rapport and trust with the interviewee. Such conditions better ensure reliability of the data gathered (Basit, 2010; Fontana & Frey, 2005; Harrington and Foster, 2013; Hill, 2014). This is especially important in respect of gathering data from children. I therefore planned a number of sessions. In the first I aimed to introduce myself and explain the project in order to gain the children's understanding (appendix ii) and informed consent (appendix iii). In the second I aimed to carry out the data gathering activity (photo walk or drawing activity) and in the third to interview/talk about what had been found out through the photo walk or drawing activity. The fourth gave me an opportunity to present feedback to each child and to check the reliability of my interpretation of what they had told me. Although four meetings were planned, in reality this differed between each participant, based on access and co-ordination of

times to meet; my sense of how long they could concentrate for in each session, and the method chosen e.g. the photo walk sessions took a longer time than the others.

Permission to voice record each session was sought. For one participant voice recording was a problem. He did not agree to this so field notes then became essential during and after meetings to record the details of the sessions. The data collected for three of the participants was recorded and then transcribed word for word.

Field-notes

Transcriptions of taped interviews did not produce any data about contextual information nor did it record non-verbal cues or body language that may be useful to interpretation. Therefore I used field notes as a method to collect this data. It is important to use our eyes as well as our ears and also important to do this in as systematic way as possible to ensure reliability (Silverman 2000). I followed the suggested system of making notes at the point of interview, expanding these as soon as possible afterwards (Spradley, 1979 cited in Silverman, 2000). I wrote these up in the form of a contact summary sheet which gave me the chance to make an initial analysis and interpretation which then influenced what sort of information I thought could be sought at the next contact (Miles & Huberman, 1984 cited in Silverman, 2000). I created a manageable system of keeping field notes as highlighted by Silverman (2000):

> How we record data is important because it is directly linked to the quality of data analysis. (p142)

Research log

I recognised that in gaining permission from parents and talking through what the research entailed was a dialogue that needed to be noted as, although they were not the participants in this research, they did give contextual information, thoughts and feelings which may have had an influence and may bear relevance to this study. In this respect I kept a log of conversations. I followed the same format as in collecting the field notes and recorded a contact summary sheet after every conversation (Miles & Huberman 1984 cited in Silverman 2000)

5 point scale

Scales have been used for many years to help pupils rate their emotions (Buron and Curtis, 2003). As I did not know how confident the participants were able to verbalise their ideas I developed the scale using Buron & Curtis's format (Appendix vi). This was in order that it may be used to determine participant's thinking in response to the questions asked. The aim here was that the scales were visual and reduced abstract ideas to numbers " thus matching the learning characteristics of students with ASD" (Buron and Curtis, 2003 p 1). This only became necessary in one participants interview and outcomes are discussed in part 4 - the analysis section.

3.3 Sampling and participant procedures

Narrative study samples may only focus on one or two individuals (Creswell, 2007) and may be non- representative of the population (Cohen, Manion & Morrison, 2007). The sample size was small (four participants) precluding any intention to generalise from this study. The methods of data collection in this respect did not produce data overload (Fontana & Frey, 2005) or become too demanding (Basit, 2010).

A purposeful sampling technique was used whereupon "..the inquirer selects individuals ... for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study" (Creswell, 2007, p.125). The criteria I chose for selection of participants was that: children were of primary school age (5 – 11 years of age), that they had a diagnosis of Autism or Asperger's, that the individuals included had enough language development to be able to communicate their experiences. Although my main interest lies in how children experience mainstream settings I have not precluded the views of children who attend special schools and the one participant from a special school only transferred there from a mainstream school in September 2014. The main aspect of inquiry was to gauge views of school experience and this can be regardless of setting. The final sample included 4 boys (7 – 10 years of age), one attending a special school and three attending three different mainstream schools.

3.4 Validity and Reliability

How I approached this study was important for consideration so as to determine what influence or bias could have occurred. McCormick & James (1988 cited in Cohen et al 2007) suggest that researchers, to ensure a reflexive approach, need to monitor closely "their own interactions with participants, their own reaction, roles, biases and other matters that might bias the research" (p191). I was aware of how my own experience and context could have informed/influenced the outcome of my inquiries (Etherington, 2004) and to this end I made memos on my field notes of my own responses. My position in this research that may have influenced my interpretation of the results are discussed in Chapter 4.

Being aware of our thoughts, feelings, culture, environment and personal history will determine how we talk to people, transcribe conversations, interpret and represent others (Etherington, 2004). By seeing the relationship between researcher and the interviewee as collaborative, what I am hoping to achieve is a "sense of power, involvement and agency" (Etherington, 2004, p32) for the participants.

One of the ways I chose to ensure reliability and validity of responses was to use participant validation (Basit, 2010). Transcripts of recorded conversations were made word for word. In order to ensure a fair representation of what was said a summary of what the children had told me was shown to them so they could check that I had correctly represented what they had said (Basit, 2010).

The relationship between interviewee and interviewer and any power differential that may occur could potentially be heightened as this was a child: adult interview scenario (Corbett, 1998; Fielding, 2004). In order to make the children feel more at ease, settings in which to carry out the interviews were chosen with a view to where the child would feel most comfortable; three were carried out in their school place settings and one was carried out at home. Sessions were 30 – 60 minutes long depending on which method children chose to use. However if I felt the child was tired, or seemed disengaged I would draw the session to a close, asking first if the child felt we had finished for today.

3.5 Ethical Considerations

Ethical considerations were adhered to throughout the project. It was essential that all the individuals involved in the project have given their voluntary informed consent to take part (BERA, 2011). There is little guidance given, as to the ethical considerations one needs to address in research which involves children and questions around how much children understand and are able to give informed consent arise (Lindsay 2000). Lindsay questions whether the child truly understands what the research entails, what it is about and how it will be used. His examples involved research into educational interventions and their effectiveness and I can see how, in those particular contexts, children may not realise what part they play in the research unless it is explicitly explained to them which may influence any results. However I feel the study in this case involved a participatory approach and direct conversations with the participants about their involvement were sought throughout the sessions.

Lindsay (2000) also suggests that it is especially important that the researcher has the right qualifications and competence to carry out research with children. I have been an Infant school teacher for 23 years and also recently completed a masters level course in research methodology so feel I have the relevant competencies to carry out this project.

In the case of this study parental consent was necessary due to the age of the children (appendix v). However assent was also sought from the children and no one took part unless they are happy to do so (appendix iii). Care was taken to explain the reasons for the study and assure confidentiality and anonymity especially as the sample size was so small. Pseudonyms are used to protect anonymity. In assuring confidentiality I was also aware that should a disclosure of a sensitive nature be made, that might make me feel that the child may be a subject of abuse, this would have had to be reported appropriately according to local safeguarding procedures. No disclosures were made. I also had to gain consent from the schools as I met three of the children on school premises for all of their sessions and needed to liaise re convenient meeting times, so as not to disrupt children's learning, and also seek permission to walk around the school for the photo walk (appendix iv). All permissions were granted.

The right to withdraw was explained and before each session started I checked that the children were still happy to take part thereby reviewing assent throughout the project (Lewis, 2002; Lewis & Porter, 2004). Assent or any dissent can be difficult to notice in young children and Ann Lewis (2002) suggests keeping an open dialogue with all those around the child in order to pick up any signs of dissent if this is not immediately obvious from the child. I made sure that parents were fully informed of each session before it took place and checked after each that their children were happy to continue. Some say engagement with the activity is another way to gauge assent (Harrington & Foster, 2013) and I was careful not to make assumptions, and observed behaviour and responses carefully during the sessions. I have judged these to be positive from the responses I observed.

The best interests of the child are the major consideration at all times (BERA, 2011). This was especially pertinent as interviews were used as a methodological tool. Trust, rapport and sensitivity need to be developed with no abuse of power that may distort or influence responses and put undue pressure on the respondent (Lewis, 2002). Consideration regarding this have been outlined in more detail in the validity and reliability paragraph.

Data is sensitive in nature and to this end access remained confidential to the researcher and supervisor of the project, with assurances to those taking part that this would be the case. Data stored electronically was password protected and paper copies locked away for the duration of the project with the assurance that all personal information would be destroyed after the duration of project. I agree with Lindsay (2000) that it is imperative that

> Practitioners should respect their participants, in their interactions, in the tasks they set, and in their treatment of information which they acquire (p19)

I feel I have carried out the protocols and followed a code of conduct expected of one doing research so that my behaviour would be seen as professional, sensitive, respectful using appropriate language and expression in all situations according to BERA (2011) ethical guidelines and professional protocols.

Chapter 4 – Results & Analysis

4.1 Introduction

This chapter presents the results and analysis and includes:

- The approach used to analyse the data;
- An overview of the sample and contextual information;
- The results and analysis for each participant detailing what the children said about their own perspectives of school?

4.2. The process of analysis

The data collected was in the form of transcribed interviews, field notes, memos and contextual background information provided by parents and teachers. Field notes and memo's formed an important part of the data as well as the transcribed interviews (Huberman & Miles, 1994), especially as one child did not want his voice to be recorded.

The analysis was carried out in stages following a thematic interpretative approach (Huberman & Miles, 1994) . Each stage of data collection constituted an opportunity for analysis (Brinkmann & Kvale, 2014, Maxwell, 2005). Transcripts and field notes were processed straight away after each meeting. An initial analysis was made of these, which involved writing memos outlining thoughts regarding each interview around broad themes that emerged from both verbal and non-verbal communication. This analysis then informed some of the content during subsequent interviews. A report, derived from what each participant had said, was shown to the children so that they could comment on, correct or include further information. The next stage was to read through all the transcripts, field notes and memos. Categories were highlighted that related to the questions posed based on the interview schedule. These could be termed as organisational categories as they were pre-determined (Maxwell, 2005). The transcripts, field notes and memos were then read again to highlight any other common themes, especially those that were child initiated.

The following categories for analysis were identified:

a. **Likes and dislikes**: this category was directly linked to questions asked in order to gauge children's enjoyment of school.
b. **Support and difficulties**: this category was linked to the way the children perceived how they were supported at school, what helped them to learn and what aspects of school they found difficult.
c. **Social relationships** underpin many of the characteristics of autism so this was included as a category to analyse any responses made regarding friendships or otherwise.
d. **Response to the process of the interview** was identified as a category to gauge, assent to the project and responses to the different facilitation processes.
e. **Special Interests**: areas of interest initiated by the children
f. **Silence and non verbal communication:** recognising that gestures, expressions, pauses and silence may be communicating a meaning

4.3 Overview of participant information

	Harry	Dominic	Emile	Luke
Age	7	8	9	10
Diagnosis & when	Autism (a year ago) ADHD	Asperger Syndrome (approx. when he was 5 years old)	Autism (at end of year 4)	High Functioning Autism (During year 4)
School	Independent Special School	Mainstream Roman Catholic local authority primary school	Mainstream Community local authority primary school	Mainstream Community local authority primary school
Year group	Year 3	Year 4	Year 5	Year 6
Statement of SEN	Issued approx. 2 years ago	Issued during his reception year	Issued at the end of year 4	Issued in year 4
Level of support, including adult's educational strategy	School specialist in field of Autism In a class of 5 children with high adult – child ratio	3 x per week 'hub' sanctuary at lunchtimes Social Skills training Social Story about friendship	Just been awarded funding for 1 hour per day extra adult support	Visual Timetable In class support from teacher and teaching assistant
Number of meetings (hence interviews)	1	3	2	2

Each child's responses have been presented separately as, although similarities did emerge, the perspectives they portrayed were unique to each child. This individuality highlights Harrower & Dunlap's (2001) view that autism is diverse and heterogeneous in its manifestation. It was interesting to note the way the children's personalities and behaviour determined the way they approached the interview and the method they chose to engage with. All names have been replaced with pseudonyms as per ethical considerations outlined in chapter three.

4.4 Harry

Harry is seven years old and has just started at a new school, an independent special school specialising in meeting the needs of children with autism. He is in year three and will be turning eight in November. His previous school, according to his mother, had done everything they could and she had nothing but praise for them. It took a long time for the local authority to agree to fund the placement at an independent school and Harry's mother felt they wouldn't have agreed if he hadn't had a diagnosis of autism. He has had a statement of special educational needs (SEN) for the last two years, but it is only within the last year he has been diagnosed with autism. His mother reports that he is in the middle of the spectrum and also has a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD). She was worried that his academic achievements were 'way behind' that of his peers, that he could only just write his name and that he found it difficult to do the simplest of self help skills such as brushing his teeth. She is pleased with the new placement as it means he is in a class of five children with a high level of support.

4.4.1 Likes and Dislikes

He remembered his last school, smiled and said he loved being there. (This is in contradiction to what his mother had told me.) Harry was very definite about what he liked at school.

I love (emphasis) painting and the computers. (H1)

He was more hesitant when talking about what he didn't like.

There were a few things.(H2)

Gentle probing to find out if there were any situations he could relate his dislike to, for example playtimes, he either didn't respond to or became distracted by something else.

He told me he likes being at home *'yes I like being at home, yes I like staying at home' (H3)* and later in the conversation *'I can stay home (pause) forever (emphasis)'(H4)*
Harry's mother has indicated that given the choice he would stay at home all the time and that he finds it difficult to go out of the house for any reason, not just school.

4.4.2 Support & Difficulties

Harry quickly answered when asked what helped him at school and related this to the adults he currently worked with, two teaching assistants and his teacher. When asked how they helped him he said:

They give me games, they learn me have computers (pause)
and plus a few harmless things (pause)
what I hate it. (H5)

He did not expand on what he exactly hated so it is difficult to interpret whether it was something about the support or just the particular activities he was given. He steered the conversation away from this topic very quickly and when I gently tried to bring him back to this said:

Mmmm huh, that's all I hate (H6)

4.4.3. Social Relationships

When looking at a photograph of his old class he pointed to the teacher and said he didn't like her, pointed to the teaching assistant who he said he did like and then identified two children who he called friends. He did not expand on why they were his friends. In no other part of the conversation did he mention anything to do with

social relationships in the context of school. He has only been at his new school for two weeks so it is not surprising that he made no comments regarding peer friendships in that context. He loves his family and very emphatically told me so.

4.4.4 Response to the process of the interview

I met Harry at his home, as this was his preferred place to meet. He greeted me with a spiderman net shoot and grimace, but after introductions was keen to show me the game he was playing on the play station and also the other games that were his favourites. In order to facilitate a conversation about his perspectives of school, I showed him pictures from the website of his previous school and his new school. Using the computer held his interest and looking at the pictures prompted some of the comments he made. This was his preferred choice as when I also offered paper and pencils for him to draw some pictures about school, he very definitely told me he did not like drawing. *'Drawing, hate drawing' (H7)*

He was lively, enthusiastic, and funny. When he wanted to answer questions he was quite definite about what he said. He was proficient at using the computer to stop and start a video link and also freeze pictures he wanted to look at for longer. Interruptions distracted him from the conversation, and it was only when he was using the computer to look at pictures about his school was he totally engrossed. The pictures prompted descriptions about the physical environment at school.

> *Look, you go in here and that leads you to the playground, it has a swing and it has trip wire and the chickens and the library. (H7)*

He was also eager to tell me all about chickens and how they lay eggs when he spotted this on the video link. He showed engagement within the process, which indicated to me that he was happy to take part throughout the interview. When thanked he responded:

> *It's ok, it's been a pleasure, it's my pleasure to let you know (holds out his hand to initiate a hand shake) (H8)*

4.4.5. Special Interests

Harry loves comic book heroes and in particular spiderman. Although this did become a distraction during the interview it did not interrupt it so much as to detract from the interview process and information gained.

4.4.6 Silence and non-verbal communication

Harry moved around the room a lot before he settled down to talk. If there was an interruption, such as his father coming into the room, he was instantly distracted and would get up. However, he did show he was engaged with the conversation as he would sit really close and answered questions quickly. He became engrossed in the pictures he was looking at of his school on the computer, so much so he often would not hear the questions and this was the only time he was silent.

4.5 Dominic

Dominic is 8 years old. He currently is in year 4 of a Catholic mainstream, local authority, primary school and has attended the school since he was in playgroup, from the age of 3 or 4 years old. His diagnosis of Asperger syndrome was made when he was about 5 years old and he has only recently been told of it. According to his mother the school have been very supportive of his idiosyncrasies, for example when he was younger he had a fascination with lifts and in order to be able to enter the classroom made pictures he could press, as if entering a lift, so he could go in and out of the classroom. The decision to tell him now about his diagnosis was taken as peer relationships had become more difficult for him at school. Academically he is operating at an above average level in certain subjects.

4.5.1 Likes and dislikes

He loves the special time he has at lunchtimes when he stays inside. He likes using the computers and likes Maths. He is very proficient at word processing on the computer and edited his own captions he typed for himself to annotate his photos. While he was writing captions for the book he described how happy he was each time he changed to a new class

He doesn't like getting told off and told me that doesn't happen all the time.

When prompted as to what he may not like in the classroom – he took my question very literally and described how he hated the colour of the walls and the messy book corner. Literal understandings are a salient feature of autistic characteristics (Frederickson & Cline, 2009).

At one point though, unprompted by any question, he said that he really didn't like school and would prefer to be at home but didn't explain why and carried on typing his captions. When asked why, he didn't answer. After a while I tried to ask again why he didn't like school and he indicated in a cross voice

can we just get on with this (D1)

It was obvious he did not want to talk about it. He carried on typing saying how amazing his time in reception was.

My impression was that Dominic did not want to necessarily talk about dislikes and things he found difficult. He would fall silent or look away or steer the conversation to another topic.

4.5.2 Support and Difficulties

Dominic attributes his learning to himself and his '*brain*' (D2) and that his teacher helps him with '*the new stuff*' *(D3).* When asked what he found difficult he said he didn't know.

When I asked about a member of staff I knew supported him with social skills training he just told me that she ran the hub and gave no further detail. Is he aware of this being a support for him? Does he recognise why he is given this support?

4.5.3 Social Relationships

He talked about having a friend for tea that day, but indicated that it was not his best friend. He did not initiate any other conversations about friends and did not answer any questions about them. When greeted by any adults he was very polite in his reply.

4.5.4 Response to the process of the interview

Dominic chose to take photographs and walked me around the school taking photographs of areas and details that interested him. The following sessions allowed

us to make a book of the experience and talk more about his perspectives of school. He did not want to be voice recorded as he said his voice was *'dumb'* and *'too low'*.

I could tell he enjoyed the process of taking the photos as he interjected affirming comments after each '*excellent*', '*great*', '*perfect*' (D4). He seemed happy and relaxed for the most part as we walked around the school and he was confident to lead me to different areas and talk briefly about each. Dominic was very articulate, occasionally using phrases which bely his age:

> *This way to the playground. It looks like it is currently used. (D5)*
>
> *That bit used to be the playgroup, I went there, they call it the Nursery now. I like to call it the Kindergarten (D6)*

Kindergarten is not terminology generally used in England to describe Nursery provision. Unusual patterns of language are characteristic of autism (Fredrickson & Cline (2009).

It was interesting to note that much of the conversation was about describing the building and what happened in each bit of it rather than about him at school. For example:

> *The Allotment is one of the most unused places in the school, but it is good, full of vegetables and fruit growing nicely. (D7)*

He was very matter of fact about most parts of the school and did not go into detail, only highlighting a particular detail that might interest him, for example while showing me the door to the medical room the aspect that interested him most was the poster on the door

Was Dominic showing me areas that he thought were important to show me, as I hadn't seen the school, or was he showing me areas that were important to him, which is how I had originally introduced the activity? (see discussion on photo elicitation later in the chapter) When asked about any areas he didn't like he didn't answer.

However it was obvious which rooms interested him most:

> *The ICT suite is my favourite room. It has lots of computers. It even has a teacher computer. I like computers. (D8)* (said while he showed me where the

ICT suite was) *The ICT suite also has a wire connection with about quadrillion wires..... and an interactive whiteboard and a crucifix above it to remind us of Jesus and there's enough computers for all in the class.(D9)* (said in the following session whilst making the book)

I hang out here. I go to the hub sometimes. I come after I have had my lunch. I love hanging out here on the sofas. (D10) (this being the room he uses as a sanctuary three times a week at lunchtimes)

He did not include any adults or children in his photos, even when a teacher posed outside a door he was about to take a picture of, he waited until she had moved.

4.5.5 Special interests

He has a special interest in a particular play station game and can talk about this in great detail, quoting *verbatim the code of the game.* He likes to play the game and also indicated he is allowed to play it at school when he goes to the 'hub' at lunchtime.

4.5.6 Silence and non verbal communication

When I asked whether he would show me his 'All about me' book – a social story on how to be a good friend, he replied non-commitantly *'mmm' (D11).* He gave me the impression he really didn't want to talk about it.

I ended each the session earlier than anticipated when I could see Dominic was becoming restless, wriggly in his chair or at one point when he stopped typing, went very quiet and turned away. At that point he decided to take a break and read a book.

4.6 Emile

Emile is 9 years old and in year 5 at a community mainstream primary school. He received a diagnosis of Autism at the end of year four. His mother reported that she had been worried about Emile since he was a year old and it had taken a long time for anyone to really listen to her concerns about his lack of social awareness and interaction. He does not have any one to one support at the moment and the school are

still working on a programme that will give him individual support for one hour a day.

4.6.1 Likes and dislikes

Emile described what he liked and disliked about school. He particularly likes playing outside at playtime. He gives the impression he does lots of things on his own when he is outside.

> *I like the climbing frame (E1)* (and when asked why added) *I like can play on , play on the monkey bars and ropes (E2)*
>
> *Well I Like to play on something (pause) I didn't like (pause) Sometimes like yesterday , yesterday there was so much wind so I watched the leaves turn into tornados so I like.* (asked if there was anything else he liked doing in the playground) *If there's wind, well if there's no wind and I'm not on the climbing frame then I would like hold the pole and I would do this..*(and demonstrates with his hand spinning around) (E3)

Emile doesn't like falling over in the playground and also when people are mean to him. He indicates that being hurt by others has happened a couple of times but says it's *'rare' (E4)* .

He loves art. He likes maths but thinks he is not so good at it now he is in year 5. He is really good at handwriting but not so keen on reading story books as he doesn't understand them. He prefers reading real, non fiction books. His teacher told me that his motivation for becoming really good at handwriting was when there was a competition at school and he was determined to win. Even though he does not like reading fiction books he told me how he entered a summer holiday reading competition.

4.6.2 Support and difficulties

Emile says the teacher helps him learn at school when he is shown what to do and given examples. When he gets stuck his teacher or friends help him.

He says he finds science difficult but then qualifies this with saying he thinks it's boring and he is not interested in it. He is not sure what 'topic' is but then gives a very lengthy explanation about how it changes each term and actually last terms topic was Anglo Saxons. I am not sure he really knows what 'Science' is but knows it has something to do with topic which he is unsure of.

4.6.3 Social relationships

Most of the things he likes doing in the playground he does alone. The only time he mentioned any friends was when he invented a game, which he ended up playing with one other child.

4.6.4 Response to the process of the interview

He was quiet and thoughtful, taking his time to answer questions, often searching for the right words to use. Emile chose to do drawings about school but when he wanted to start he seemed a little unsure of himself and asked for confirmation about what to do. He expressed a contemplative interest in watching natural things happen. When we met the second time he seemed a little more confident and was smiley and friendly. He affirmed that he likes coming to school and likes 'the playtime'. He chuckled to himself about a game he had invented. He had some good ideas about what could be improved in the playground for him.

4.6.5 Special Interests

His mother had told me that he is interested in earthy things and gemstones. Although he did not specifically say this was his interest, his expressiveness about the wind, watching leaves and his idea for one thing to change at school was to make potions and gemstones.

4.6. 6 Silence and non-verbal communication

Emile spoke slowly and often took his time to think about what he was saying. I could tell he needed time to formulate what he was going to say so there were lots of silences between his phrases. His speech often trailed off as if either he wasn't sure what to say or he didn't have the confidence to say something. He generally looked out of the window as he spoke but would turn and give eye contact when he was

finishing what he had to say. He would smile and often demonstrated with gestures what he was trying to communicate, for example when describing a piece of play equipment he had seen in a park and how he could make it work using his own energy.

4.7 Luke

Luke is 10 years old and in year 6 at a maintained local authority primary school. He was diagnosed with High Functioning Autism (HFA) while in year 4 (8 – 9 years old). He received one term of small group work support regarding social skills training while he was in year 5. He does not have any one to one support, however the practitioners (teacher and teaching assistant) working in his classroom provide individual support should he need it. There is a daily timetable he can refer to and he is told of any changes that may occur. He is above average in ability in certain subjects.

4.7.1 Likes and dislikes

> *Maths (pause) playtime (pause) PE (pause), I hate singing, singing assemblies (L1)*

> *Sometimes do boring stuff – boring to me. Science – that's quite boring. Literacy – sometimes good, sometimes boring. Comprehension can be quite fun. (L2)*

Luke was very articulate and spoke quickly. He spoke a lot about playtime (mentioned below in social relationships) and what games he liked to play outside, although he said his preference was *'Well talking mostly' (L3)* to his friends.

4.7.2 Support and difficulties

When he is asked what helps him with his learning Luke attributes the way he is helped to learn at school from his own abilities.

> *What does? So (emphasis) if I learn at home and I do the same thing at school I am good, but you know I said I like maths, that's because, well like, for every lesson, ummm, I'm good at it. I don't need any help (L4)*

He does not mention any support from any adults and when asked specifically if he is supported by any adults, says '*no*'

What about things that are more difficult for you?

> *That's only when I get bored and I daydream (pause)*
> *Or or I daydream or I really don't understand it. That hasn't happened for along time actually, the last time it happened in class* .....(here he switches instantaneously to talk about things he does with his friend at playtime) *I didn't know what we had to do as me and A ok were .....for quite a for about a year no wait not a year about six months we were bullying girls (L5)*

The question in my mind is has he changed subject because he doesn't want to talk about what's difficult or has he not understood the question, or is the bullying something he found difficult too, or is it an area of interest that he would prefer to talk about?

4.7.3 Social relationships

Luke gave me the impression he had close friendships with at least three other children, one being his best friend for about six years. He was keen to tell me about all the trouble they got into at playtime in the playground and even admitted to bullying two girls. He returned to the topic of playtime three times to tell me more things he had got into trouble for.

4.7.4 Response to the process of the interview

Luke was, at first, interested to take photos and show me around the school rather than draw. However, he then changed his mind and said he preferred to just talk. He was very articulate, confident and aspirational, much of the conversation was about what he would like to do when he grows up and what he needs to do in order to get there. In much less detail he talked about likes and dislikes at school but was far more interested to steer the conversation to things he had a particular interest in. He was confident in his own abilities. He was smiley, friendly, forthcoming and seemingly relaxed. However he professed a preference that he would like to stay at home and when asked, tried to explain why, saying quite a few things bore him. He gave me the

impression this was because he was not interested rather than finding anything difficult.

4.7.5 Special interests

He spoke about his special interest in a particular cartoon programme, which he then described in detail. He was very interested in telling me about which school he really would like to attend next year when he moves on to secondary school. He was preoccupied with this subject, as well as the subject of playtimes, returning to each throughout the interview. I wondered whether these preoccupations came from a positive or negative viewpoint. For year 6 children this is the time of year when they and their families have to make choices and apply for which secondary school they will be moving on to. He was very definite in his ideas of where he wanted to go. Was he worrying about this process? He talked a lot about getting told off. Was he worried about getting into trouble at school?

4.7.5 Silence and non-verbal communication

There was only a small amount of silence when he did not answer a question about what he found difficult at school. His conversation went from one topic to another almost instantaneously. He maintained good eye contact throughout.

Chapter 5 – Discussion

5.1 Introduction

This chapter is presented in two sections.

- Methodological Analysis includes an evaluation of the methodological tools chosen - how successful were these methods in gaining the perspectives of the children?
- Discussion in relation with links to the literature review, what did the voice of the children tell us?

5.2 Review of methodological tools used

Curtis, Roberts, Copperman, Downie & Liabo (2004) suggest that disabled children are less represented in the range of research that explores their perspectives, than children who are easier to interview. In this respect the authors argue that it is difficult to draw upon the practical lessons of previous research, as difficulties are not well documented. They suggest it would be far more helpful to be open and frank about the difficulties so that consequent research can build and develop better research practice (Curtis et al, 2004). Preece (2002 cited in Brewster & Coleshaw, 2010) suggested that it might be more difficult to access the 'voice' of children with autism because of the very characteristics autism itself. Research has shown that very young children are able to speak confidently about their likes and dislikes and evaluate their learning, making decisions as to what they should do next (Clark & Moss, 2011). It was therefore surprising that the children in this study gave short responses to many of the questions directly linked to the subjects of likes, dislikes, support and difficulties. Some interesting questions arise from this. Was it to do with the children's autistic characteristics and the nature of autism, as previously suggested by Preece (2002). Or was the difficulty the children had in answering the questions linked to methodological tools chosen for this study. The lack of research in interviewing primary aged children with autism about their school perspectives does not allow for any guidance in which methods may work better. Therefore the interview process used in this study, merits close scrutiny. With this in mind the following evaluation of the research process chosen to be followed, may highlight

which methods worked well and what could be improved when considering future research.

5.2.1 Questioning skills, types of questions – open or closed?

Jill Porter (2009) raises some important questions regarding questioning skills used in gaining views and perspectives of children with learning difficulties and/or with social and emotional behavioural difficulties (SEBD). Although SEBD children are in category of special educational needs very different from that of autism, I would suggest that the considerations are similar when it comes to thinking about what type of question to use. Also consideration as to what, during the interview, probing questions the researcher uses in order to try and encourage further talk. In this present study, questions developed were open ended after careful consideration of previous research, albeit with secondary aged pupils with autism. However, during the interview the pre thought questions were phrased in quite different ways, depending on the participants responses. Porter (2009) confirms that flexibility in re phrasing questions is a valid way forward, as it depends very much on the child. Responsiveness to questions from the child is an unknown until you have actually started the interview. The children interpreted some questions in a literal way, which gave seemingly odd answers not in line with the intention of the original question. For example, when Dominic was trying to answer questions about what he found difficult, a prompting question was made asking him what he didn't like or found difficult in the classroom. His immediate reply was to describe how he didn't like how the classroom was decorated and that the other children weren't very good at keeping the classroom tidy. Literal understanding is a salient characteristic of autism (Fredrickson & Cline, 2009). Phrasing questions, which didn't exacerbate a response in this way, was incredibly difficult. The children found it difficult to respond to questions, which were asking them to think about what supported or helped them at school. Also to questions about what they didn't like, found difficult or what didn't help at school. Research has shown that children and very young children, are able reflect upon their learning, identifying strengths and what they need to do next (Clark & Moss, 2011). Children with autism have more difficulty in understanding abstract ideas or ideas that are not presented in context (Fredrickson & Cline, 2009). What

supports or hinders learning at school is quite an abstract concept and taking into consideration that the interviews were done out of the context of the classroom this may have added to the difficulty the children had in answering these questions.

5.2.2 Interviews – whose agenda?

Lewis & Porter (2002) have indicated that careful thought needs to be given as to exactly what motivation is there behind interviewing children. The authors go on to say that, the challenge is not to over formalise the process of hearing children's views, especially when professionals are under pressure to gather these views because of government policy initiatives. Is the interest of gaining pupils perspectives, initiated by researchers or schools interests, or is it coming from the child's interests? In this study it was to gain the child's interests. After interviewing the first child, a memo made asked whether the questions asked were leading, or interrupting the child's thoughts while he typed his perspectives of school on the computer. Dan Goodley (1998) describes how he put off his first informant by being too enthusiastic and making the informant feel 'grilled' and suggests that there are two conflicting ways of thinking about interviews. Should the interview be the agenda the participant sets, in this study the child's interests (Lofland, 1971 cited in Goodley, 1998) or encouraging the agenda the researcher sets, in this study the interest of finding out the ways the children perceived support or what they found difficult (Tremblay, 1959 cited by Goodley, 1998). In this present study, from analysis of the transcripts and field notes time was given to explore both the perspectives of the child and the interests of the researcher, with a bias towards hearing about the interests of the children foremost as the conversations led in that direction. Collecting the views of children should be seen as a conversation not a checklist to be ticked off (Porter, 2009). After the first interview, silence was used as a way to give the space for the children to think about what they wanted to say (Morris, 2003) and to acknowledge silence as a form of communication (Booth & Booth, 1996).

5.2.3 Photo or drawing elicitation

Drawings have the potential to help children to talk about their experiences that may have gone unrecognised before (Leitch, 2008). Photographs, in a similar way can elicit details that children may not have given just by answering a question and are

concrete visual reminders (Hill, 2014). Only one child completed the task of taking photographs to illustrate what he could tell me about his school experiences. His descriptions were mainly technical and descriptive. Had he understood the activity, as his descriptions were about the building (previously referred in Dominic's analysis), or was this another literal understanding of the intention of the activity? Kaplan (2008) in his use of photographs in participatory research with secondary aged children with learning difficulties, stresses the importance of longitudinal projects. The inference he made was that it is important to build up relationships, in order to gain a 'true' perspective and he argues that "short-term or one off participatory image-making projects, offer the least opportunity for depth and increases the potential for misrepresentation and misuse of data on all sides" (Kaplan, 2008. p189). The interpretation given to Dominic's response was that he was immensely proud to be a part of his school and in taking the role of an ambassador to show the researcher around could be empowering. Subsequent conversations and how he annotated his pictures gave detail to the areas, which were important to him – the ICT suite and the hub and less detail for those areas that were less important to him. Any more time spent with the photographs may not have elicited any different views from Dominic as he was confident in his approach to the task and took charge, illustrated when he took over typing his captions himself. Kaplan (2008) suggests being wary of over interpretation as this may render the 'voice' meaningless and devalue the child's intentions. Even though Dominic had taken quite a literal understanding of the task, the photographs facilitated further conversations about his views of school.

A slightly different approach was taken with Harry as he chose to stay at home to talk to me, so we were unable to walk around his school. Photographs were not then of his making and images were taken from the school websites. Caution re interpreting the ensuing conversation needs to be taken as Porter & Lacey (2005, cited in Porter, 2009) says of an activity, which entailed sorting photographs chosen by the researcher, "On the one hand the photos provided a good ice breaker introducing a joint activity that facilitated interaction.....but on the other hand it gave the boys a false sense of what the 'activity' was about.'" (p356). However, it could be said that although the activity, in some respects, did not elicit so much detail in Harry's remarks, it did allow prompts regarding his likes and dislikes about people and things

at school. Harry was engaged with the task and without this facilitation, it was felt he would have not responded so well to interview questions.

A question arose as to the way to interpret Emile's hesitancy in drawing his pictures as art was his favourite subject. It may have been down to his understanding of the instruction or it could have been that, just as with his speech, in that he took time to formulate what he was going to say, it also took him time to formulate what he was going to draw. He drew two pictures depicting his favourite equipment in the playground, one of the climbing frame and one of the swing chair. Interestingly he did not draw himself, or any one else, on them. The drawings did facilitate the ensuing conversation, in what Hannah Mortimer (2004) describes as a springboard for further talking and thinking together. Emile went on to talk about the system the school put in place to organise who could use the equipment in the playground. He also described the way he liked to use the equipment, which then led to a conversation about what improvements he thought could be made to make the playground more interesting for him.

In conclusion it would seem that using photographs and drawing to facilitate the interview process had some success in eliciting the views of the children. The caveat is that conclusions can only be tentative, and not generalised to other children with autism as the sample size was so small.

5.3 Links with Literature Review

5.3.1 Nature of Autism

Many of the comments the children made, the way they were expressed and the behaviour the children demonstrated could be attributed to the characteristics of autism. Talking in detail about special interests, only being motivated in subjects that they found interesting, describing activities as being boring to them, and very little conversation about social relationships, all relate to the manifestations of the criteria for autism, the detail outlined as in chapter two. All of these factors varied considerably between the four boys and concurs with the view that there is huge variance across the spectrum (Harrower & Dunlap, 2001; Powell, 2000).

The sense of aloneness that came out Emile's conversation, echoed one of Kanner's (1943) original criteria of autism. In answer to various questions about whether he played with any friends in the playground or on the equipment he liked to use, he said he was on his own. He only mentioned playing with another child, once. One interpretation could be that he may prefer to be on his own. Or a judgement might be made 'oh poor Emile he doesn't have any friends so he plays on his own'? An alternative interpretation could be, that he enjoyed just 'being' and the playground gave him a great source of satisfaction from being close to nature, watching natural phenomenon and enjoying the sensations of 'spinning and swinging' on different equipment, as detailed by his answers (see earlier results section). Higashida (2007), as a thirteen year old with autism, when reflecting on question's "Do you prefer to be on your own?" (p47) and "Why do you like spinning" (p101) says that he finds people who describe him as a person who prefers to be on their own actually makes him feel lonely rather than it being true.

> The truth is, we'd love to be with other people. But because things never, ever go right, we end up with getting used to being alone, without even noticing this is happening (Higashida, 2007, p48)

And of spinning,

> Us people with autism often enjoy spinning ourselves around and around..... Everyday scenery doesn't rotate, so things that do spin just fascinate us" (Higashida, 2007, p101)

We cannot assume that Emile might be 'lonely'. He does, however, enjoy watching leaves '*spin around like tornados*'.

McLaughlin & Rafferty (2014) have criticised previous research on pupil perspectives, suggesting that the analysis in these studies, dwelled too much on characteristics of autism and therefore did not truly focus on the young persons perspectives. I would suggest that it is difficult to ignore these characteristics as understanding of them allowed a more meaningful interpretation of what had been said. The caveat to this is that characteristics should be viewed positively. The results of the conversations gave an overall impression about 'who' these children were, their personalities shone through and this was not defined by their autistic characteristics.

5.3.2 Educational Strategies

The three children in mainstream did not have one to one, in class support from learning support assistants. Only Harry referred to how his teaching assistants were able to help him with his work. Luke could refer to a general class timetable regarding the organisation of the day (visual timetable), but did not attribute this to helping him. Only one child, Dominic, was receiving some social skills training and had a social story prompt to help him with thinking about the way to be a good friend, but he did not refer to this at all as a way of supporting him. However, he loved the 'hub', a place where he could withdraw to at lunchtimes and pursue his particular interests. He did not attribute this as a strategy of support. Sainsbury (2009) recounts in her earlier childhood how she welcomed the chance to be allowed to come inside at lunchtimes. She stated that teachers can have an immense chance to make a difference in accepting special interests and taking the time to let them be explored. Both Harry and Emile's responses portrayed that they recognised that teachers were there to help them. Emile explained in detail that if he was not given the examples from the teacher he would not understand what to do. In an earlier chapter personal accounts from people with autism highlighted the way in which strategies used by teachers could either hinder or support their time at school and consequently their learning. The children's accounts, in this study, did not mention any particular educational strategy such as a social story or visual timetable in this way. The question arises as to the level of understanding the children would have about the concept involved in supporting or hindering their own learning.

The concept of learning and what may support or hinder this process in any one individual are very abstract concepts. Children with autism do have more difficulty, than other groups of children, understanding abstract concepts (Jones, 2002). Research has shown that a range of methodological tools may help access children's views on what hinders or supports children in their learning (Georgeson, 2012). Methods such as , picture cues, talking mats, customized questionnaires (Lewis & Porter, 2004; Georgeson,2012) may be worthy of consideration with children with autism. Porter (2009) stresses the importance of finding appropriate methodologies "to turn the argot of adults to that of children" (p353). The issue of being able to self

evaluate one's own learning is an important issue to consider when the imperative is that children with special educational needs should be involved in drawing up their own educational plans of support.

Dominic and Luke could tell me straight away that they were good at Maths. Emile could tell me he didn't enjoy reading story books because he couldn't '*summarise*' them. This suggests some evidence that the children were able to evaluate their learning. Acknowledging that this is quite an abstract concept for any child, it then becomes even more of a challenge for children with autism as discussed previously. It may have been more pertinent to have concrete examples in front of them, regarding their academic work in order for them to relate directly to what they are being asked to reflect upon. However, this may not be so easy regarding evaluating any social support strategies. Dominic did not seem to want to talk about his 'All about me book', a social story used to help Dominic cope at playtimes. It was difficult to interpret why and although he was asked, he didn't bring the booklet to any of the meetings. The implementation issues of social stories are discussed earlier in chapter two (Dedridge, 2007). No firm conclusions could be drawn from Dominic's response. Confidence to express ones opinion and views could have been an issue, and research has identified that 'Children need to feel 'licensed' to make their voices and views known and this is only likely to happen if they feel confident' (Mortimer, 2004, p173).

5.3.3 Pupil Voice

A) Informing planning

As demonstrated and discussed in earlier chapters, listening to the views of children about their school experiences gives insight into how teachers can plan the next steps of children's learning both academically and socially (Carrington & Graham, 2001; Humphrey & Lewis, 2008a, Saggers et al, 2011). It was also suggested that this is not just about listening but about acting upon what is heard. What follows is an illustrative exercise that shows the way the interpretations of what the children said in this particular study could be realised in planning their next steps. It should be noted that these are the researchers interpretations and just an example as to the way a

teacher may evaluate the conversations. These are presented in the form of questions, which inform lines of inquiry to be thought about when supporting the children both academically and socially.

Harry is struggling academically. How can Harry's interest and competence with computers be capitalised on in his writing, as he finds writing by hand so difficult and not interesting.

Luke find's school boring, yet he is articulate and has aspirations to go to Oxford University. Could his specific interests be utilised in a more cross curricula way to motivate him in a broader range of subjects?

Is Emile being bullied? His mention of incidences of unkindness from other children warrants investigation and requires immediate action.

Emile had really good ideas on how to improve the playground – are there systems in place whereby his views will be valued?

Is Dominic struggling with his identity? Are his swings from being happy one moment to saying how unhappy he is in the next any indication that this might be the case? How is the social support currently in place being monitored and evaluated?

The children's own teachers would obviously have much more information about the children, on which to guide their planning.

Without talking to children or taking the time to build those relationships which Jones (2002) says are so crucial to develop in order to listen more effectively, information gathered by listening to the perspectives of children with autism cannot be realised.

B) Accessing views

The two younger children in this study, Harry and Dominic found it quite difficult to articulate any difficulties they may have had. Jill Porter (2009) discusses the challenges of accessing children's views and suggests it takes time to access thoughts

especially if they bring bad memories for the child. It is not to be suggested that Harry and Dominic necessarily have bad memories but that in general children find it more difficult to talk about things they don't like or find hard and other studies indicate that children may find it embarrassing to talk about things that are difficult for them (Woolfson et al, 2007 cited in Porter, 2009 p 354). Challenges in finding the right questions and the skill in questioning itself are highlighted by Porter (2009) and discussed, in an earlier section, in this chapter.

C) Comparison to previous research

Drawing on research exploring autism and pupil voice as outlined in chapter two the research found the predominated perspectives of secondary aged children focused on the children's struggle with identity, social relations, incidence of bullying, and the stress of *'in class'* factors. In contrast the topics that all of the children in this study were able to talk about in detail, were about their particular special interests, which were not school related. For three of the children their perspectives were heavily based on the physical characteristics of school, with little mention of peer relationships. For a different three children they all indicated they would prefer to be at home. No firm conclusions could be drawn from these comments as to whether this was because they were having any difficulties at school. It was hard to draw any other commonalities between the four children, as their perspectives were very individual and also difficult to draw any conclusive comparisons between this study and previous research.

In chapter six, an evaluation and conclusions drawn from the preceding analysis and discussion will be presented.

Chapter 6 Evaluation & Conclusion

6.1 Introduction

This chapter will present an evaluation of the present study and the way in which the findings relate to the research questions posed. A review regarding how successful the methodological tools had been in eliciting the views of the children with autism was previously outlined in chapter 4. However, further discussion about methods and recommendations for the future will also be included in this chapter. Implications for future research, drawn from the findings, regarding pupil voice of primary aged children with autism, will also be included. Finally, limitations to the study will be presented.

6.2 Were photograph and drawing activities successful in facilitating the interview process?

This study has highlighted some success in using photographs or drawings to facilitate the interview process with children, in that these methods generated longer interactions and elicited more detail in responses. However, difficulties arose in children accessing questions that could be linked to the characteristics of autism. These difficulties were linked to the children's tendency to interpret questions literally and secondly, having problems in understanding more abstract concepts in some questions. One of the greatest challenges for a researcher is to develop appropriate communication skills and also to find the best way in which this can take place (Lewis & Porter, 2004). Constrains have been suggested by researchers, that electing to use just one method may limit the meaning you can draw from the conversation and conversely by using a variety of methods may elicit interpretations that could either be conflicting or confirming (Lewis & Porter, 2004). There seems to be advantages and disadvantages whatever method is used to draw out children's perspectives. Further investigation as to which methods may be more appropriate when interviewing children with autism is required to generate any firm conclusions. However, the implication from the results of this study is that schools need to think carefully about the methods they use to facilitate seeking the views from children with

autism and these methods may be very individual in nature, building on children's own preferences and strengths.

6.3 Was the study successful in answering the research questions?

What do primary age children on the autism spectrum say about their school experience?

The accounts each child gave emphasised the children's uniqueness and their different personalities. A real sense of who they were and what they were interested in was communicated in the way the children behaved and from what they said. Individual perspectives of school grew as each child focused on diverse topics and areas of interest.

The children were confident to talk, some more articulately than others. The willingness to take part was shown in the positive way the children behaved and from the engagement they showed throughout the project, especially during the drawing and photograph activities. Some questions elicited more detail and a more positive response than others. All the children could talk about what they liked about school. Some children, more than others, could talk about what they disliked about school. The study to some extent was successful in gaining the views of what children with autism could say about their school experiences. The suggestion put forward is that accessing the views of children with autism is perhaps more difficult because of the children's social interaction and communication differences characterised by the nature of autism. It is then up to educators to come up with ways that are more conducive in eliciting the children's views. These conclusions cannot be generalised as the sample size included only four children. However, it is proposed that further research, looking at the different ways professionals can encourage children with autism to voice their views and opinions, is recommended to find out which method may be more effective.

The findings from this study differed in focus from those gathered by previous research with secondary aged pupils. Secondary aged pupils were concerned with struggles of identity, social relations, incidences of bullying and organisational considerations of the environment. The topic of conversation from the children in this

study focused on their individual areas of interest, which were quite diverse. For two of the children their main interest was computers, for another two the subject of maths absorbed them, whilst one focused on his fascination with nature and another was very aspirational about what he wanted to do when he was older. Only one child talked in any detail about social relationships. The interpretation of the difference in perspectives between the findings of secondary aged children and that of primary aged children, could have been age related and/or connected to environmental differences in the way primary and secondary schools are organised. Hard conclusions about the comparison between secondary and primary aged pupils cannot be drawn, as this was beyond the scope of this study.

Following the main question above, two sub questions were posed about the perspectives of children with autism.

What experiences help and support them?

What experiences do they find a challenge?

The children were less confident in evaluating the supports and barriers to their learning. In order for children with autism to directly be involved with any decisions made about the best way to support them at school, their skills in evaluating and being reflective about what works best for them academically and socially need to be developed and encouraged. In this respect another implication for practice is that it is not just that schools/teachers who need to develop their own listening skills, but also for schools/teachers to enable and develop children's skills in self advocacy. This is especially pertinent for children with disabilities and as Georgeson (2012) suggests listening by teachers and being able to express ones views by children "....takes time, not only to prepare appropriate materials" to facilitate listening " but to introduce children to the concept of self-advocacy and to develop the confidence to express their own opinions." (p1609).

It has been said of teachers, discussed in an earlier chapter, that they need to have a better understanding of the nature of autism and how this links to learning in order to plan more effective educational plans, to address both social and academic needs for children with autism. Although the research questions posed did not demand that the results be analysed as to how the responses could be interpreted in order to inform

planning next steps for each child, the responses were very illuminating in identifying possible areas of development for each child. The suggestion proposed is that this understanding is crucial in order for educators to, first of all be able to listen and secondly, to then act upon what children with autism tell us. 'Acting upon' includes not just action, but also to appreciate and accept, a different point of view.

How ever difficult it may be to listen to the views of children with autism it is imperative that schools find sensitive ways to encourage children's communication (Lewis & Porter, 2004). The methods used to gather views or the lack of understanding of children with autism could be said to be the limiting factors to listening. Another barrier, to be overcome could be time. Research found that the prevalent view put forward by teachers which discouraged them from implementing ways to seek views from children was the length of time it took to make it meaningful and embed practice (Flutter & Rudduck, 2004). Research recommends that when it comes to listening to children's voices it is not a process that can be rushed (Lewis & Porter, 2004). Tensions in education exist, with schools struggling to find the time for competing agendas. The results agenda is still very much at the fore and often in opposition with the inclusion agenda, which demands a different kind of focus and time to embed good practice (Barton & Armstrong, 2007; Corbett & Slee, 2000; Wedell, 2008). With the implementation of a new Special Educational Needs and Disabilities code of practice, the imperative of consulting and listening to the views of children has been re – emphasised (DFE, 2014c). Schools must make sure they find the best ways to listen to children's views in order to enable all groups of children to take an active part in the decision making that affects planning for their learning and support. Research recommends active listening to the voices of children with autism puts school in a better position to "collaboratively create supportive learning and social environments" (Saggers et al, 2011 p173).

Research demonstrates the far reaching effects of listening to the voices of children and young people in improving schools and improving outcomes for children. (Flutter & Rudduck, 2004; Jelly, Fuller & Byers, 2000; Rudduck & Flutter, 2004). From these studies it was shown that self-esteem and confidence were raised in children (Jelly et al 2000). Teachers were more effective in their planning for the children's needs (Flutter, 2007). In a comprehensive longitudinal study in special schools, Jelly

et al (2000) explored the effects of putting whole school plans into place which developed pupil involvement in developing individual education plans. The results revealed that pupils became more engaged in their learning and aspirations for the future were raised (Jelly et al, 2000). Statistics regarding the outcomes for adults with autism show that two thirds of adults do not get the support they need and one in three adults with autism experience some kind of mental health issue because of this (Rosenblatt, 2008). Only 15%, of adults with autism gain full time employment (Redman et al, 2009). Education plays a crucial role in developing ways that involves the participation of children and young people in decision making as demonstrated by Jelly et al (2000) project where "pupils can become effective managers of their own learning within a context of wider school improvement and developing inclusion" (Sebba, 2000, the forward, cited in Jelly et al, 2000).

6.4 Implications for practice and recommendations for the future

From this study understanding the nature of autism and developing ways to communicate more effectively are seen as key factors to enable teachers to listen more effectively to the voices of children with autism. Research has indicated that teachers lack confidence and awareness of what is the best way to support the learning, academically and socially, of children with autism (Helps at al, 1999). Knowledge and awareness in school staff needs to increase, but a criticism is that there is no training strategy in place to address this (Jones et al, 2008). Therefore two recommendations are put forward. Firstly that, schools put in place appropriate training to develop the skills and knowledge of teachers and school staff to understand the teaching and learning implications for children with autism. Secondly, to develop methods, in conjunction with developing staff listening skills, in order to access the views of children on the spectrum.

Listening to the views of children on the spectrum is underexplored in the field of research (Humphrey & Lewis, 2008), especially in the primary school age range. It is the recommendation of this study that further research is supported to address the gap that exists in understanding the implications that arise from listening to the voice of children with autism in primary schools.

Listening to children with autism, should not be seen in isolation from the rest of the school. Development of a whole school ethos, making sure that any marginalised groups have an opportunity to actively participate in their own educational plans, whole school improvement initiatives should be the imperatives of schools. With this in mind a recommendation would be for schools to develope children's self advocacy skills.

And lastly from the voice of a young person with autism:

> *Don't assume you know what the child is like if you have read a manual about autism. There are as many brands of autism as there are autistic people. Look and listen to the individual person..... (Darius cited in Sainsbury, 2009)*

6.5 Limitations of the study

This was a small scale project, with only four participants, based an a qualitative design approach. It would not be appropriate to generalise the results to a larger population and therefore constitutes a limit to this project.

Research has emphasised that it takes time to gather the views of children, certainly when different techniques are used, to make interpretations meaningful (Clark & Moss, 2011; Lewis & Porter, 2004). The short time frame in which this study was carried out therefore, could be seen as a limitation.

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Appendices

Appendix i Interview Scedule

Listening to the voices of children with autism spectrum disorders about their experiences of school.

To facilitate this the child is asked to show the researcher around their school and to take photos of what is important to them, what they like about the school and what they don't like about the school. (An alternative to this would be if the child likes drawing, they could draw pictures about school)

The pictures are then looked at on a computer to help facilitate a conversation about what the child does or doesn't like about school. (If the child wants to, a book is made with them annotating in their own words pictures they have chosen to be included in the book)

The following questions are explored through this process.

What do you like about school?

What don't you like about school?

What activities do you like at school?

What activities don't you like?

What helps you learn at school?

What do you find difficult at school?

Appendix ii

Framework for conversation with participants re Informed Consent

Introduce myself - that I go to college, that I am learning about children with Autism and Asperger's and that I would like to find out what its like for them at school.

(I think it is important to establish who I am as opposed to other adults in their lives as they will have come across many professionals and may be hesitant/wary of adults intentions)

Explain what will happen – that I would like to find out what it is like at school for ..... what they like, what they don't like, what helps them , what doesn't help them. In order for us to remember the conversations we have had I will use this (show phone/recorder) to record our voices. In order to remind us what it is about the school we like we will use this to take photos (show the camera). Have you used one of these before?

Demonstrate how each device works.

I will offer the choice of drawing pictures instead if they don't want to use the camera.

So next time we meet I will visit you at school and you can show me around the school and take pictures to tell me about your time at school. Would you like to do that?

It would be their choice if they want to show it to their parents or their school, but they don't have to. I will be writing about what I find out and I will let them see the things they tell me so they can check if I have written down everything they want to tell me in the right way.

Appendix iii Child Consent form

Project: Finding out what experiences (name of participant) has at school.

Becky would like you to show her around your school and tell her about the things you like and the things you don't like?

Becky would like to record what you say to her?

Becky will write about your experiences and show you what she has written so you can check it is right.

Becky won't use your name when writing about your experiences.

You can tell Becky at any time if you don't want to talk to her anymore.

I agree to taking part in this project:

Appendix iv School Consent Form

University of Roehampton London

European Commission ERASMUS MUNDUS

INFORMATION SHEET AND CONSENT FORM

Project title: Pupil Voice: Listening to the voices of children with autistic spectrum disorders about their primary school experience

Researcher: Becky Underwood

Supervisor: Professor Jan Šiška (Charles University – Prague)

This document consists of two parts. Part 1 holds information about the project of research; Part 2 is a certificate of consent.

Part 1: Information sheet

Introduction

I am a postgraduate student completing my Masters dissertation at Charles University, pursuing an Erasmus Mundus MA in Special and Inclusive Education. Currently I am in the process of conducting a study for my dissertation as partial fulfilment of the degree's requirements.

Purpose of the research

The research is intended to find out the perspectives of pupils with Autistic Spectrum Disorders about their school experiences. It is hoped that these perspectives will inform relevant practice and help educators to plan appropriately to meet the needs of children on the Autistic Spectrum.

Research procedures

Meetings will be held with the participant in order for them to get to know the researcher and in order for them to understand the study and how they will be involved. They will then be asked to participate in either taking photos, drawing pictures or in a way they choose to convey their perspectives of their school experience. All conversations with the participant will be audio recorded (only with their permission) and notes taken. Taking photos will involve walking around their school (with the schools permission). The photos will be taken in accordance to school policy.

Voluntary participation and right to withdraw

The school's participation in this project is entirely voluntary. The school may withdraw from the study at any time, or request that information gained would not be used in the study. The researcher is obliged to honour this agreement.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however, the school's name or other identifying information will not be used or revealed. All personal information you provide will be kept strictly confidential, separate from the interview data and kept on file for the duration of the study. At the conclusion of this research project I will destroy all computer and paper records containing your identifying information. I will be the only one to have access to any personal information.

Contacts

Should the school wish to seek clarification or further information, you may contact me through the following email address: underwob@roehampton.ac.uk or mobile number 07743973545

Part 2: Certificate of consent

This school has been invited to facilitate a study on Pupil Voice: Listening to the voices of children with autistic spectrum disorders about their primary school experience by letting the participant and researcher walk around the school taking photos (adhering to any school policy).

I have read the information above and have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily for this school to be a part of this study as prescribed by the research procedures above.

Name of School:.....

Headteacher's signature.....

.....

Contact details of school.....

.....

Date:.....

Appendix v Parent Consent form

University of Roehampton London

European Commission ERASMUS MUNDUS

INFORMATION SHEET AND CONSENT FORM

Project title: Pupil Voice: Listening to the voices of children with autistic spectrum disorders about their primary school experience

Researcher: Becky Underwood

Supervisor: Professor Jan Šiška (Charles University – Prague)

This document consists of two parts. Part 1 holds information about the project of research; Part 2 is a certificate of consent.

Part 1: Information sheet
Introduction

I am a postgraduate student completing my Masters dissertation at Charles University, pursuing an Erasmus Mundus MA in Special and Inclusive Education. Currently I am in the process of conducting a study for my dissertation as partial fulfilment of the degree's requirements.

Purpose of the research

The research is intended to find out the perspectives of pupils with Autistic Spectrum Disorders about their school experiences. It is hoped that these perspectives will inform relevant practice and help educators to plan appropriately to meet the needs of children on the Autistic Spectrum.

Research procedures

Meetings will be held with the participant in order for them to get to know the researcher and in order for them to understand the study and how they will be involved. They will then be asked to participate in either taking photos, drawing pictures or in a way they choose to convey their perspectives of their school experience. All conversations with the participant will be audio recorded (only with their permission) and notes taken. A feedback report will be shown to the participant, once collated so they can check that their perspectives have been truly represented.

Voluntary participation and right to withdraw

Your child's participation in this project is entirely voluntary. You or your child may withdraw from the study at any time, or request that information gained would not be used in the study. The researcher is obliged to honour this agreement.

Confidentiality

Information gathered in this research study may be published or presented in public forums; however, your child's name or other identifying information will not be used or revealed. All personal information you provide will be kept strictly confidential, separate from the interview data and kept on file for the duration of the study. At the conclusion of this research project I will destroy all computer and paper records containing your identifying information. I will be the only one to have access to your personal information.

Contacts

Should you or your child wish to seek clarification or further information, you may contact me through the following email address: underwob@roehampton.ac.uk or mobile number 07743973545

Part 2: Certificate of consent

My child has been invited to participate in a study on Pupil Voice: Listening to the voices of children with autistic spectrum disorders about their primary school experience

I have read the information above and have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily for my child to be a participant in this study.

Name of Participant:.....

Parent of Participant signature .....

Contact details .....

.....

Date:.....

Appendix vi
5 Point Scale